



# **When a Child is Diagnosed with Autism**

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## **When Your Child is Diagnosed with Autism**

Emily Perl Kingsley explains it best in her writings titled "Welcome to Holland". In this short insightful script, she compares the feelings of a parent whose child is diagnosed with a disability with a beautifully planned vacation that has gone off course, landing the parent in Holland instead of Italy. Kingsley touches on the feelings of shock, disappointment, and loss; but also on the continuation of that unexpected "vacation" and all the wonderful things it still holds, even though it is not what you had planned.

When your child is diagnosed with autism, you experience a rollercoaster of feelings and emotions. Do not lose sight of what is important – your child's future. It may not be as you had dreamed or planned but it still lies ahead and how you approach the future can make a world of difference for your child, your family, and yourself.

## **What is Autism?**

A diagnosis of Autism Spectrum Disorder (ASD) or Autism as it is more commonly known refers to a complex developmental disability that affects the way children develop and behave. Autism usually makes its appearance in the first three years of life, although it may not be diagnosed until later.

Autism is referred to as a Spectrum Disorder because it is comprised of a defined combination of symptoms that cross a range of what should be typical development. The combination of those symptoms and the severity of each symptom may vary with each individual.

## **Typically, Children with Autism Display:**

- impairments in social skills and relationships
- impairments in verbal and non-verbal communication
- self-restricted, repetitive and atypical behavior, interests and activities
- atypical sensitivities to daily stimuli of sound, taste, smell, touch, and/or pain

Autism affects the way individuals are able to communicate, develop relationships, cope with and function in society. It causes problems socially, because it affects their ability to understand social norms and non-verbal communication or, in more severe cases, the ability to communicate verbally. It may cause atypical repetitive behavior, or behavioral reactions to stimuli that do not affect the rest of the typical population.

For a more detailed description of diagnoses and symptoms, please see our booklet *What is Autism?* available from the Autism Society of Edmonton Area.

## **What do Children with Autism Need?**

Individuals with autism have to be taught what is normally taken for granted. Most children will learn to communicate, engage others, and play; through the normal course of their daily lives. Children with Autism do not pick up on what seems to be learned through osmosis by their peers. Normal exposure is not a sufficient enough learning ground for these children. They need to be taught in a method that works for them at a speed at which they can absorb what comes easily to others.

Autism is currently thought to be a lifelong condition but that does not mean it is life ending. Children with autism may have difficulty with social relationships, but that does not mean they cannot participate in the world around them. Given the opportunity, these children can learn the necessary skills to hone and display their intellectual, artistic, or physical talents like other children; whether it be art, math, playing the piano, tae kwon do, swimming or even playing soccer. The question is where to start, and that depends on you and your child.

## **What do I do if I Think My Child has Autism?**

If you suspect your preschool age child has autism, contact your physician or pediatrician, for a referral to have your child assessed. Families within Edmonton and the Capital Health Region are referred to the Preschool Assessment Service (PAS) at the Glenrose Rehabilitation Hospital. Older children must also be referred but to an assessment service geared for older children, which is also at the Glenrose Rehabilitation Hospital. The wait time for such an assessment can be lengthy. Be prepared to be flexible with your time since early diagnosis means early treatment and intervention for your child.

## **Assessment**

An assessment will be completed by a multi-disciplinary team. The team will assess your child's cognitive, social, fine motor, gross motor and language skills as well as their physical condition as compared to age-appropriate development. If a diagnosis is confirmed by this assessment, you will receive a written report from each member of the team explaining the diagnosis and severity of symptoms, as well as written recommendation for treatment, usually ABA or IBI (Applied Behavioral Analysis or Intensive Behavioral Intervention). This can be a stressful experience for parents, but remember it is a necessary first step in seeking appropriate treatment for your child. This information will be the foundation from which you begin your journey and treatment for the betterment of your child and family.

If you are unsure whether your child has symptoms of autism, but you have suspicions regarding hearing or language/communication abilities, you may also consult your local health unit. They will be able to direct you or, in some cases, arrange and appointment for a speech and/or hearing test. The health unit is not permitted to confirm or deny diagnosis of autism. For families in the Edmonton and Capital Health region, a diagnosis of autism can only be made by formal assessment through the Glenrose Rehabilitation Hospital.

## **Knowledge is Power**

While you wait, adopt the attitude that knowledge is power. Waiting can create its own sense of urgency, so seek out information. Use your local library for books or magazine archives which contain informative article about autism. There are also thousands of sites to reference on the internet. Contact local organizations and seek out as many parent contacts as possible. The Autism Society of Edmonton Area will be happy to have a parent volunteer contact you at your request. Simply call us at **453-3971** or email us at [autism@autismedmonton.org](mailto:autism@autismedmonton.org).

Don't be afraid to ask questions. Ask the same question of many different families. Each case may be different, but there is something to learn from each experience. Those who live the experience have a different perspective from those who study the topic. Create a filing system of boxes, binders, file folders, etc. to collect and organize information. You will be amazed at how much you can gather. This will help you make informed decision regarding your course of action. If you feel overwhelmed, uneducated, or powerless; being proactive will give you a sense of control and focus.

## **Help and Support**

Remember there is help and support through this journey. The Government of Alberta, Family Support for Children with Disabilities (FSCD) provides family support services and child focused services for families of special needs children. These services can be accessed through a caseworker at FSCD, who will provide you with information on the services available based upon the range of issues impacting your child and family. You may contact FSCD at **1-866-346-4661**. In addition Program Unit Funding (PUF) through Alberta Learning is available for preschool children between 2.5 and 5.5 years of age for a maximum time of three years. This program allows your family to access a variety of early education programs best suited to the needs of your child and family. These programs include in-home, daycare, community or school board supported sites; and they offer a variety of specialized services that work with your child's abilities and challenges. A referral for funding by this program is provided when a preschool age child is determined to have a significant developmental delay. Contact your local health clinic for referral to an appropriate assessment site.

There are a number of support groups, including emotional support groups and parent groups that share information on a variety of topics ranging from biomedical to sensory processing therapies. These groups generally meet once a month and may ask for a nominal contribution towards facility rental.

For a current list of support groups, meeting times and places, contact the Autism Society of Edmonton Area. For a list of other potential services, request our booklet "Services You Should Know About".

## **Therapies**

You will discover there are many different therapies available for the treatment of autism. It is important to realize that individuals and groups invest time, energy, and money to study a particular therapy and they truly believe in their method of treatment. Autistic children are diagnosed with a spectrum disorder, which means they experience a range of symptoms and severities. Many therapies may work on one symptom while leaving other symptoms unattended. One form of therapy does not work for every child, nor can it guarantee the same results for everyone. Do not feel pressured into accepting one form of therapy at the expense of other therapy options. Do your research. Ask questions about success rates, qualified case studies, and the symptoms and diagnosis of those involved. Speak with parents about therapies they have used and ask how successful they were for their children. Consider your child's specific needs and challenges and make your own informed decision on the best course of action. The most important thing in all of this is that the therapy proves to be beneficial for your child.

## **Assessing Therapy Success Rates**

For a fair evaluation of any therapy, avoid the temptation to start more than one form of therapy at a time. One aid to determining how successful a therapy is for your child is the Autism Therapy Evaluation Checklist, otherwise known as the ATEC. This is a questionnaire designed by the Autism Research Institute (ARI), which is one of the best known research facilities for autism. You can find them online at [www.autism.com/ari/atec/index.htm](http://www.autism.com/ari/atec/index.htm) or the Center for the Study of Autism website at [www.autism.com](http://www.autism.com). Click on the link for the Autism Research Institute and perform a search for ATEC. It is a survey you can complete online which helps you monitor the benefit of any therapy you choose to follow. The questions cover speech, language, communication, sociability, sensory & cognitive awareness, and health & physical behavior in the form of a "less to more" survey format. Once completed, your answers are calculated and provide you with a numerical scale or representation of severity in each of these categories. You can complete this questionnaire at any time during the course of therapy to see if it really is benefiting your child. It is a very helpful resource parents can use on their own without having to consult a physician or professional therapist. Best of all, it is based on your experience with your child.

## **Autism Society of Edmonton Area**

The Autism Society of Edmonton Area (ASEA) is a not-for-profit, charitable organization dedicated to creating a community in which individuals with Autism Spectrum Disorders (ASD) are valued for their potential.

### **ASEA Offers:**

- Parent Support Groups: for parents of individuals with autism or asperger's syndrome.
- Parent Information Evenings: talks on a variety of autism-related topics are presented once a month from September to March.
- Library and Resource Materials: including books, periodicals, conference proceeding, articles, CD's videotapes, and DVD's.
- A Quarterly Newsletter called Autism Now
- Family Programs: a summer aide program and various social activities for people with autism/PDD-NOS/asperger's and their families.
- Advocacy and Partnerships: advocacy support for inclusive education placements; education program liaison with EPSB autism sites; ASEA initiated and chairs the Autism Collaboration Team with professionals in the field; representation to government focus groups and committees; and member of the Autism Society Alberta and Autism Society Canada

Website: [www.autismedmonton.org](http://www.autismedmonton.org)

## **More Information**

The Autism Society of Edmonton Area (ASEA) does not endorse or recommend any method, product, remedial center, program or therapist for people with autism related conditions. ASEA believes that individuals have the right to access all available information and make their own decisions. With this in mind, we offer the following websites as useful resources that provide basic information on Autism Spectrum Disorders and many others links to a variety of informative sites on autism.

[www.autismsocietycanada.ca](http://www.autismsocietycanada.ca)

[www.cairn-site.com](http://www.cairn-site.com)

[www.autism.net](http://www.autism.net)

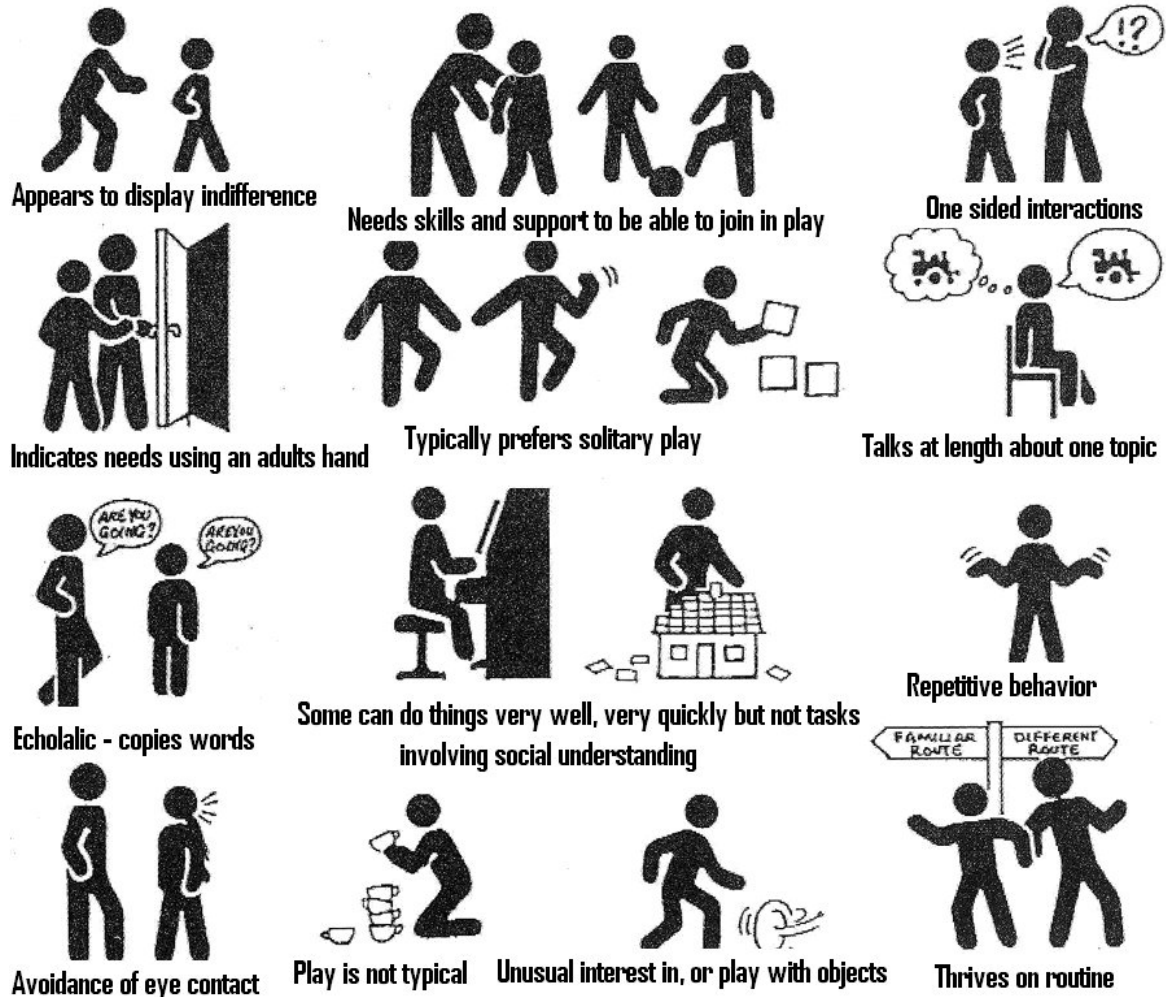
[www.autism.com](http://www.autism.com)

[www.autismspeaks.org](http://www.autismspeaks.org)

For more information contact the Autism Society of Edmonton Area at (780) 453-3971 or email [autism@autismedmonton.org](mailto:autism@autismedmonton.org).

# Autism is:

These figures illustrate some of the manifestations of autism. Not all persons with Autism experience each of these symptoms and they vary in severity.



Early diagnosis is essential if people with autism are to achieve their full potential. It is only when their disability is understood that they can be helped to maximize skills and minimize problems.

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